

PUTTING THE PATIENT BACK IN PATIENT-CENTERED CARE

MARCH 30, 2011

COLLIN: Hello, and welcome to the AHRQ webcast. This is on the topic of the National Web-Based Teleconference on Health IT: Putting the Patient Back in Patient-Centered Care.

At this point I'd like to introduce today's moderator, Angela Lavanderos, who is a program analyst with the Health IT Portfolio, Agency for Healthcare Research and Quality. Angela, the floor is all yours.

ANGELA LAVANDEROS: Thank you, Collin. Before we begin today's session, I am required to read the following statement for CME purposes. This educational activity has been approved by the Wisconsin Medical Society for 1.5 AMA PRA Category 1 credits. Speakers and planners are required to make disclosure of any relevant financial relationships which may be related to the subject matter discussed. Speakers and planners for this educational activity have made proper disclosure and have no relevant financial relationships that exist now or in the past 12 months.

With that, I would like to introduce the speakers for today's teleconference. The first speaker is Dr. Paul Tang. He is an internist and vice president, chief innovation and technology officer at the Palo Alto Medical Foundation, and is consulting associate professor of medicine at Stanford University.

Dr. Tang also directs the David Druker Center for health systems innovation and oversees Palo Alto's electronic health record system and its integrated personal health record system called My Health Online. He received his B.S. and M.S. in electrical engineering from Stanford University and his M.D. from the University of California, San Francisco. Dr. Tang is an elected member of the Institute of Medicine and serves on its healthcare services board. He is a past chair of the Board for the American Medical Informatics Association. Dr. Tang is vice chair of the Federal Health Information Technology Policy Committee and chair of its Meaningful Use Workshop. He is also a member of the National Committee on Bio and Health Statistics and co-chairs the NCVHS quality subcommittee. He received the 2009 AMIA Don E. Detmer Award for Health Policy Contributions in Informatics.

Our second speaker is Dr. Elizabeth A. Chrischilles. She is a professor at the Department of Epidemiology and holds the Marvin A. and Rose Lee Pomerantz chair in public health at the University of Iowa, College of Public Health. Dr. Chrischilles is principal investigator of two research centers funded by the Agency for Healthcare Research and Quality, the University of Iowa Older Adult Center for Education and Research on Therapeutics called the Iowa CERT, and the Iowa Developing Evidence to Inform Decisions about Effectiveness Center, the Iowa DEcIDE-2 Center.

Dr. Chrischilles is also principal investigator for an AHRQ grant being discussed today regarding the role of personal health records for improving medication use quality. This grant began with physician focus groups within a practice-based research network to determine the value and uses of a personal health record for their patients and was followed by a multidisciplinary participatory design to build an Internet-based personal health record focusing on older adults. The project is now in the midst of a randomized controlled trial of that PHR. Dr. Chrischilles received her B.S., M.S., and Ph.D. in pharmacy from the University of Iowa, College of Pharmacy.

Our last speaker today will be Dr. Silke von Esenwein. She's an assistant research professor at the Rollins School of Public Health at Emory University and collaborates with Dr. Benjamin Druss on several federally-funded projects. These projects aim to develop and test new evidence-based strategies to integrate services and improve health in persons with serious mental illnesses. She also works closely with the Carter Center Mental Health Program, which seeks to reduce the stigma and discrimination against people with mental illnesses and to increase public awareness about mental health, as well as working with the Jane Fonda Center, which is exploring the need to alter current sex education frameworks to intersect more dynamically and meaningfully with the future.

She has a longstanding commitment to improving the lives of persons with mental disorders, particularly those in poor, underserved communities. Dr. von Esenwein received her Ph.D. in neuroscience and animal behavior from Emory University in 2005.

So with that I'd like to kick off our teleconference. Dr. Tang will begin the webinar with an overview of a tool designed to assist diabetic patients manage their condition via an online tool.

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DR. PAUL C. TANG: Thank you very much. We'll move over to talk about Managing Health and EMPOWERing Patients, and I'll go ahead and explain the word "empower" even though I'll talk about it a little later. But it takes two people to create a name for a project: One to create the name and two to make it make sense. Somebody made this make sense by saying engaging and motivating patients online with enhanced resources, but it truly is empowering patients as we're going to talk about.

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We're going to start by looking at the traditional disease management, and we're going to be talking about an online disease management, and particularly one that personalizes healthcare for an individual, and then close with the randomized clinical trial that we've called EMPOWER-D.

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The traditional disease management everybody's familiar with is largely telephone-based. Usually a nurse is calling up patients at home, managing, usually a single disease, it might be

heart failure, it might be diabetes, and there's a lot of overhead associated with that. There's telephone tag, and it's usually a scheduled kind of a visit.

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In the new version, we'd like to talk about how we might personalize that and make it online so that it's more continuous. But first let me talk a little bit about the word personalizing and start out with personalizing the - instead of a personal health record, a personalized health record.

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Begin with looking at the individuals and their lives and their perspective, and the individuals I want to talk about are folks with diabetes. One of the questions we pose to them is what would you like your doctor to know that you don't think they already know? So that's a personalized personal health record.

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And one of the comments we got back from an individual with diabetes said, "If I could do all the right things, could I reverse the diagnosis?" Well, I think you'll recognize that that's actually a missed opportunity since these are all people with type 2 diabetes. And while there's not a cure around the corner for everyone, there are certainly ways that, without medications, you can attenuate the disease, at least in many folks. But not knowing the answer to that question and not having it explained, and not having it explained in an effective way, clearly is a missed opportunity.

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Another comment we got was, "Well, I'd like to be healthy enough to give my daughter a kidney because she's in kidney failure." Now while that's not talking about that individual's glucose or sugar, which is what everybody gets yelled at about these days with diabetes, it is a personalized - what we would consider a personalized health goal for that individual.

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And similarly, one person wrote, "I want to live to be 90." And again, none of these folks wrote about the goals for their sugar, but really portrayed "What is my individual goal that relates to my health?" And I think that's what we want to make front and center.

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So we created a program for personalized healthcare. When we talk about this, we mean customized care that's delivered online, but we're supporting - we become the support staff for patients managing their disease, but it's very customized to their individual goals that involve their health. And like many or most disease management programs, this is made up of a

multidisciplinary healthcare team; it has a physician, nurse, dietician, clinical pharmacist as a member.

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How do we do this in the online fashion, in terms of making it personalized? Well, we start with the information that we know about the patient, and that's on the left side; that may be information originally in the paper record, information that patient is to gather, like checking their sugar, and information that they enter, let's say, on the survey so we can learn more about them and their interests. That gets entered in the electronic health records system. I'm going to switch over to the right side and talk about this personalized care plan and feedback.

So we meet with the individuals and understand not only their disease, but, in a sense, their agenda; what are they willing to work on. In diabetes, they could be working on weight, they could be working on their diet, they could be working on more regular taking of their medication, or lots of things, but focusing in on what's most important or what they're ready to change, for example.

So some of the tools, and I'll go over this a little bit later in the talk, include a personalized dashboard for them. Now, how do you get from the left side, all of this information, to the right side of personalized care? And that we've created a reasoning engine that's actually - we'll call Predict - it was a program that we acquired that sort of matches the two when you combine it with what's below, which is the best practice management advice or clinical guidelines.

So you take the information, combine it with clinical guidelines, and importantly, the information we're getting from patients about their personal agenda, and we put it through this reasoning engine and come up with a personalized care plan that is shared between the patients and their professional healthcare team. It also adds decision rules that are triggered off of this individual's goal.

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So here's an example of that personalized dashboard. It starts off with this green area. And again, so what's the goal of this patient? And this comes from one of these patients who indicated that they want to share with their provider or their provider team that they want to live to be 90, so that's the goal put in front of this individual. There are other things that support that goal, but that's job one.

We also sort of translate, you know, the glucose goals into things that mean more to the patient, so that's in this next section, where it talks about your chance, your ten-year - this is just [framing him] (ph) risk - your ten-year risk of heart attack or kidney failure or stroke, et cetera - because patients are more interested in relating to their lives or people they know who had diabetes, perhaps, and said, "I want to avoid planning on dialysis," or "I don't want to have a stroke" or "I don't want to lose my leg." Those are things that are far more meaningful to the individual than the sugar.

So a combination of "I want to live to be 90" and "What things am I afraid of or that I don't want to incur"; that's front and center to me.

So then we move on and say, well, what things do we track in order to prevent, let's say, a heart attack, and those are illustrated in the red. So this individual has hypertension, is overweight, has a high LDL; those are things that are going to impact their risk, his or her risk, of a heart attack, so we're starting to connect the dots of this is why we're worried about some blood pressure or why we're talking to you about your weight or trying to reduce your cholesterol is because we're trying to avoid the heart attack that would prevent you from living to 90.

And then on the right-hand thing, okay, so what are the things that we're doing to try to affect these parameters? Well, these are your medications that affect the things on the left column that impact your ability to live to 90, and these are the things we'd like to check on periodically to try to avoid problems, and so on and so forth. So this becomes a personalized dashboard for a person with diabetes who wants to live to 90.

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So that's nice; that's where I stand. How do I deal with day-to-day life? And this is where we sort of connect the dots with activities of data (ph) living, in a sense.

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But traditionally we say, well, we'd like you to use this really nice gadget, this glucometer. It's very compact; it spits out your sugar in five seconds or less. And in order to track it over time we asked the patients to jot it down in some diary, and then go ahead and make an appointment to see us maybe every quarter, maybe every six months. Go through all the trouble of making the appointment, taking time off work for family, and visiting us in the office so that we, in our all-knowing state, can analyze the information that comes out of this glucometer and make some adjustments in the plan. So with the passage of time, it's sort of small wonder that there's (ph) really little connection between what they did to cause a reading out of the glucometer and what happened to them over the long period and what impacts "I want to live to 90."

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But what if we went online? This gadget is so nice that it generates electronic data. Why are we making them go through all these paper processes to get it to us? In fact, why do they even have to get it to us? So if we eliminate this writing on paper and then hand-carrying that in, and go straight to passing it on to us and themselves, we can get rid of this time barrier and put them, most importantly, more in control of their disease.

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So that's what we're trying to accomplish. How do we do that? By taking the reading essentially directly out of this gadget and uploading it to us. But three years ago when we started this project, there were no wireless ways to get information from a glucometer. You could plug it into a PC, but not too many people carry around a PC during the day.

So we work with a company; our metric is to create a Bluetooth adapter that would connect to this device and wirelessly upload to something they do carry around, which is a cell phone, and that cell phone would, in turn, relay that up to our servers. That puts it into the form, a graphical form, so that patients can analyze their data, and patients can react to that and decide what behaviors produce better results and what not so good. And, oh, by the way, we have a carbon copy since it's in our servers and we can make comments where appropriate so they're just in time at the teachable moment.

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So what's in the capital (ph) of what it might look like? Well, in this individual they're tracking their carbohydrate intake, and you can see this downward trend in carbohydrate intake. And likewise, this person is recording fasting and pre-meal glucose; you're seeing an equivalent lowering of their blood glucose, so that's sort of a connecting-the-dots function.

Now, we're not all perfect, so sometimes you notice some of these exception points and we do give patients the ability to write their excuse down, so in this case this patient went up for a restaurant meal at that time. And so that gives them the ability to track it and to understand what causes the ups and the downs, and as you can see here she got back on target afterwards.

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So before doing - as I said, we conducted a randomized control trial. Now, before doing that, we had alpha and beta tests, and after the beta test we invited them back for a focus group to help us understand what was it like.

Well, initially when they start talking about, you know, why did you start checking your glucose more often and doing this process of uploading? Well, it's because I'm in this program and that means people are obviously interested in me. And besides, Kelly, who was our diabetes nurse care manager at the time working with this group, was watching. And so knowing that someone else is watching, and particularly a healthcare provider, and someone who knows you and is supporting you is there, sort of gives you additional motivation that's engaging and motivating patients to work at taking a more active role in their care.

So as I illustrated with that graph, it quickly becomes learning from the data. So the notion that eating makes a big difference in my readings, now, you might think that they know that, but it's sort of the difference between seeing an individual stock price or score versus seeing it in context, in a graphic form. That's what I think connects the dots and makes the data come to life and start being correlated with individual behaviors.

So this person says, "Well, what I eat affects the reading." In fact, in one case one of the beta patients talked about he likes beer and found that taking regular beer sends his glucose up, but light beer doesn't so much, so that was something he learned.

And another patient talked about his desire to eat ice cream, but knowing full well that would shoot his glucose up, where upon a third patient said, "Well, you know what I do in that case is I walk first and that will lower my glucose and then I can have my - enjoy my dessert and that will bring it up to normal. So it's that kind of learning but also sharing in this environment that was we think very impactful.

And so finally it goes from doing it for us to learning something to essentially changing their behavior; at least that's the theory. So now if I'm going to eat something, I think about what my reading will be and so I don't eat it, and I've incorporated some of these tools in my daily life. So that's where we think that this kind of always-present, this mobile ability to not only check your reading but get the results back in a way that can influence your health behavior, can be important. As I say, we started this three years ago. Now there's more tools to do this coming up; it's far more convenient.

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As I mentioned, this is an AHRQ-funded trial called EMPOWER-D for diabetes.

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And it is a trial that involved 400 diabetics, actually more than 400 diabetics, split into intervention and control, control being usual care. Our main outcome measure is hemoglobin A1c, and other secondary measures include blood pressure and the LDL, the weight, microalbumin, their behavior and their satisfaction with the service, as well as looking at but not looking at - in a rigorous way, looking at utilization.

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So in summary, I think what we try to do is a couple things; one, make it far more convenient and with them rather than having them chuck things in to our four walls, you know, very infrequently; really make it continuous and make it online so that the sharing and the running from the data is facilitated; that we think that personalizing the goals and what you're focusing on to the individual rather than essentially throwing the book, the same book at all patients, is going to lead to more engagement. And in a sense, they're sort of giving the tools, the data, knowledge - I'm sorry, giving the patients the data, knowledge, and tools; put them on the healthcare team. But to do this while they're not, and in itself, both EHR - electronic health records - and personal health records, we believe, are essential technologies for bringing the patients onto the workforce in management or health.

And with that, I don't know whether we're taking questions here or at the very end.

ANGELA LAVANDEROS: Yes, actually. Thank you, Dr. Tang. I was going to say to the participants who have already submitted questions thank you very much for those. And we are going to keep on rolling through the webinar and take all questions at the end.

So with that, Dr. Chrischilles will now share her AHRQ-funded research examining the improvement of medication management in older adults using a freestanding online personal health record with a decision evaluation component.

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DR. ELIZABETH A. CHRISCHILLES: Well, thank you, Angela, and thanks to all the attendees for participating today. And as Angela said, today I'll be presenting works in progress on our AHRQ-funded grant titled Personal Health Records and Elder Medication Use Quality.

But the goal of my talk today is going to be to describe how older adults participated in designing and are now using a stand-alone Internet-based personal health record for medication and therapy management.

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So there's a variety of definitions out there for personal health records, and they do actually vary considerably in features, cost, and the various functionality. So what they share is that they are managed, shared, and controlled by the individual, the individual patient or consumer, which could also be delegated to a caregiver or somebody else, but it really is under the person's own individual control.

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So this slide really gives you a visual image of the world of personal health records. There's high variability across different types of personal health records, including the types of providers that are offering them, their cost, the features they include, the functionality, whether they're tethered to a health plan or integrated health system versus being freestanding, whether the patient can actually enter or change information versus a more sort of passive portal to the electronic health records, so there's a variety of ways these personal health records have evolved.

But perhaps just to highlight some particular functionality that seems to be fairly common and that suggests that personal health records could be potentially an incredible tool for enhancing patient engagement. Those functions would include the ability to import and view healthcare encounters, perhaps also prescription drug history from providers; the ability to record and share your own information with your caregivers and providers; or receive a customized recommendation similar to what we just heard from Paul a moment ago.

So in context for our project, there are now several converging lines of evidence, including the growth of the oldest old segment of our population; the prevalence of multiple chronic conditions

and associated multiple providers; fragmentation of care; discontinuities and discrepancies in medication lists; all of which point to a crisis in medication safety and adherence among older adults. Against those adverse trends, we are beginning to see an encouraging rise in personal health records nationally.

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The hope for personal health records is that they will facilitate greater control and involvement in health and healthcare among patients; also, that they will increase communication and facilitate communication between patients and their providers and caregivers and support medication reconciliation activities; and lastly, that this will actually enhance communication sharing, will reduce the stakes by both patients and providers.

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But there are some challenges, and there's considerable reason to be concerned that the individuals who are most likely to benefit from these tools are also perhaps most likely to face challenges in using them. They're typically designed for younger computer users, and older adults will face some barriers, at least generally speaking, and these would include areas such as low computer literacy and low access to computers, as well as cognitive, perceptual, and motor declines.

Other general areas include just whether the interface fits the user needs, requirement for expected data entry with some systems, and perhaps unclear value, especially when there is limited feedback functionality from the personal health record.

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So in this context, our study has the following three goals: First, we intended to investigate the usability of some commercial personal health records by usability among older adults; then our intent was to conduct participatory design to build a personal health record prototype that is specifically designed with older adults and for older adults; and lastly, to conduct a field trial to establish whether the personal healthcare record achieves engagement, a greater engagement, self-efficacy, better medication management, improved communication, and improved medication quality.

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So for our usability goal, we began the study in 2008, and obviously the field has moved rapidly, but at the time there were 58 personal health records listed in myphr.org that we were able to review. And we reviewed them with an eye toward whether an older adult would be able to use them and whether it would serve the medication therapy management needs of older adults.

We found 12 out of the 58 that might have been potentially used, but even among those there were real challenges: Poorly designed forms, navigation that was difficult, and complex user

interfaces. Nevertheless, we found one that we thought was probably the best shot at proving use was older adults. We tested that in a human-computer interaction laboratory among 12 younger adults and 12 older adults and unfortunately found that that commercially available PHR was just not conducive to medication management activities among either younger or older adults.

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So we scratched our heads and decided that instead of moving directly into the field trial of this commercial PHR we would instead move up one of our secondary aims, which was to develop a prototype for older adults, instead build a fully functional personal health record in collaboration with older adults.

So we conducted 12 sessions over an intensive three-week period with one group of older adults in a retirement community. We began wide open, without anything to show them, just to get them to imagine what a system like this could do and gradually led up to developing a prototype.

And one of the things we found that was a surprise to us was that older adults expressed an interest in entering and keeping track of health information. This was somewhat counter to what we had read in a couple of focus group papers that suggested that patients don't want to record their own information, and in fact that did not seem to be the case.

So the prototypes we built were then tested in focus groups of other older adults, tweaked a bit, and then finally built into a fully functional PHR, which we subjected to human-computer interaction laboratory testing with older adults, and the lessons we learned from that we used to modify the program.

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And the result was finally a fully functional personal health records that we call IowaPHR. It has a simple user interface and navigation, which I'll just show you in a few screenshots. But just to reiterate, in its present form it relies entirely on patient-entered information; it's an untethered personal health record.

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So this just shows a little bit about the - gives you a visual image of the simplicity of the interface. We use a lot of white space, and this is just the basic log-in screen.

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Here you see the home page and the basic setup of the personal health record. It makes use of sort of a file folder type structure with tabs for each of the functions. You can also see that there's a limited set of functions, which we also determined from our feasibility laboratory that individuals weren't willing or interested in keeping track of information, but just sort of a small list of types of information they wanted to keep track of.

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This is the medication list page, and it illustrates, in this case, medication being entered. And you can see that the medication options here make use of an ordered tree structure, so in this case the person is entering Advil. They type in the first three letters and they see Advil. If they were to click on this, this would then expand and give them more specific options so they can choose the exact right formulation of Advil.

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If they happen to enter a medication for which there is a warning about safety, then those warnings will be displayed right in the profile, right alongside their medication list, in this case Warfarin, and you see the brief alert that's listed here.

If they click on this warning, there's a short summary information, and then there's yet a third level of more detailed information supporting this. The medication warnings were based on the ACOVE criteria, which are criteria for prescribing quality for older adults, and we produced patient versions of these that identified the appropriate patient behaviors.

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Both warnings, once they're generated, now appear back on the home page so when a patient returns they'll see their latest safety updates. And you can see here just what I was saying earlier about the brief message, the summary information, and then the ability to click and get a greater detail.

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We provided an opportunity to track a small number of different types of health-related information that our participants told us were of importance to them. There's also a personal tab that behaves much as a diary that's very open-ended and they can track whatever they like.

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So I'd like to now turn to this discussion about the trial and present some basic use characteristics of the project. This was a - we had to begin by identifying older adults who were computer users, so we did this through a screening questionnaire to identify older adults who were - use a computer, and we did this by a simple random sample of a voters' registry.

Those who responded and indicated they were users of computers were mailed a baseline questionnaire that collected some of our key information and invitation to participate in the trial and were paid an incentive for completing the questionnaire.

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Very briefly, this just illustrates that those - we had about 2400 people who were actually eligible for the trial. Forty-nine percent of them actually enrolled; that is, they completed a baseline interview and sent it to us. And those who enrolled looked - [came to us] (ph) exactly like those who were eligible.

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And among the enrollees, we randomized them in a three-to-one ratio to participate in the personal health records group or the control group, and as you see here, the types of measures that we are collecting and we will be evaluating in the trial.

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I have included this slide just to show you how little interaction we've had with the users so that you can get a sense for how people are using the system. There's no training or registration. Participants simply receive a letter that includes their user name and password, and a quick start brochure is a double-sided, tri-folded brochure, and that's all they received. Up to this point, we've not spoken with them on the phone or in person. And the only time we actually talk to people is if they happen to call the help desk with questions, which happens just sporadically.

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So with that background, here's some preliminary use statistics. So in the 17 weeks since implementation, of the 873 who are invited to use the personal health records, 58 percent have logged in. And we started plateau right around it looks like eight weeks, but there was sort of a steady upswing. Let's skip over that slide.

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And here we've just described sort of how frequently people - the system is being used in a population. We're seeing about 11 different people logging in on a typical day, and then among our people who are using it, in the last 17 weeks they've logged in about 2.6 times each. And then you can see that this is a little less frequent among those who are the very oldest, 2.1 among the 80-plussers, and a little less frequency of log-ins among women.

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The average interval in days between log-ins among return users is around two to four weeks, so they're coming back every two to four weeks. Again, the oldest old and women seem to be coming back less frequently.

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Next, a little bit about what people are actually putting into their personal health records. To date, two-thirds of the users have availed themselves of the medication list function. They've entered well over 2,000 medications for an average of a little over seven medications per person; that then leaves their current medications. Three-fourths, a little over three-fourths of the user-entered medications, exactly matched the medication names in the database, so that's a pretty impressive quality of medication entry, I believe.

We haven't formally evaluated the non-exact matches, but casually reviewing those we can see that these really consist of a mixture of minor mistypings, some non-drug products, herbal remedies, and [less time at least] (ph) some actual drug names that were not in the database.

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Here's the information about the medication warnings that are being generated. Nineteen percent of entered medications have generated at least one warning. And if we focus just on the nonprescription products, let's see, which is pretty much NSAIDs, acetaminophen, and iron, although a fair share of the anticholinergics are also nonprescription, you can see that over half of these warnings are being generated by nonprescription drugs, which is really interesting in that many of the personal health records that exist do not accept user-entered or act on user-entered medication data. Furthermore, it also highlights that many of the ACOVE warnings have to do with nonprescription medication use.

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A little bit about conditions; about a third of users actually entered conditions into the condition section for an average of three conditions. There are actually around 300 distinctly different conditions that have been entered by users, which I think illustrates an intriguing potential for capturing patient-reported health conditions and outcomes that are not routinely queried in sort of standardized surveys or clinic checklists.

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This is a little bit different view of the way people are using the PHR, and this is just basically clicks on a page, so feature visits; not that they actually used the function, but they actually clicked on it, so about three-quarters of our people did appear to view the tutorial. Looks like three-quarters at least looked at the current medication list. The tracking function seemed to be visited by - about half of the people answered allergies and health conditions. The warnings pages were visited less frequently because warnings were not generated for every person.

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Some people seem to really get around and at least review most of the functionality. Now, this represents actual reports generated by users, so they tended to use most frequently the current medication list report and the wallet-sized card. The current medication list includes all their

active medications and any warnings that were generated, whereas the wallet-sized card includes the full medication list, the health conditions, allergies, and emergency contact information.

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So this has been sort of a quick survey or tour to how older adults are using a stand-alone interactive Internet-based personal health record that was designed with their input. Older adults told us during the participatory design sessions that they were interested in entering information if the design was simple. And our experience so far shows that with really no training, no person-to-person contact, and just a simple two-page quick start brochure, the majority of invited older adults actually logged on. Half of them returned to use it again and are entering health information that is of good quality, particularly medication data.

The diverse array of health conditions and over-the-counter medications that have been entered suggests some I think intriguing potential for combining the personal health record with patient registries for collecting patient-reported data and incorporating this with the information from electronic health records, for example.

With this level of use that we're seeing in a largely hands-off type of field trial it seems likely to us that we will see an effect of the personal health record on such things as keeping an up-to-date medication list, sharing the list during healthcare visits, discussing medications during healthcare visits, and perhaps also on medication quality indicators.

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So with that I'd like to say thank you to the study team, which is as interdisciplinary as it gets, from clinicians to computer scientists, and our fun group of students who also are equally interdisciplinary.

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And a few references.

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And a thank you to you all for attending, and I guess turn it back to Angela.

ANGELA LAVANDEROS: Great. Thank you, Dr. Chrischilles. Okay, we're now going to hear from our last speaker. Dr. von Esenwein will discuss the use of personal health records among patients with a serious mental illness and chronic condition.

DR. SILKE VON ESENWEIN: Hello. Can you hear me okay?

ANGELA LAVANDEROS: Yes.

DR. SILKE VON ESENWEIN: Yes, okay. I'm trying to - okay.

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DR. SILKE VON ESENWEIN: Okay. So I'm going to be talking about a PHR that did a test run on the LATCH Community Health Center that's embedded in a large public sector hospital in downtown Atlanta; they're mostly Medicaid, Medicare, or uninsured patients. It is with (ph) people that have serious mental illnesses and often had a chronic health condition, mostly cardiometabolic condition.

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Just a little bit of background, the people with serious mental illnesses have usually a number of multiple conditions, so the uses aren't only have (ph) simply depression (ph) of a puller (ph) disorder; usually they have diabetes or they're smoking and have other health - cholesterol issues. And they usually find themselves in a pretty scattered, uncoordinated system where nobody's talking to each other and there's very little information shared.

And in terms of information technology, community mental health centers lag way behind other private sector health providers. So we've actually worked in a hospital that when you discover (ph) the study largely, have had people records for their patients. It's starting to move everything now into ER, into electronic health records, but the bulk of the information still resides in large binders of very kind of disorganized - binder full of papers.

(Slide)

So we saw (ph) what PHR might be a good way to improve outcomes and get the patients more involved, because nobody's coordinating their care for them so this might be a way for them to step into this. I guess that there hasn't been much done of this, how - see if coordinating care between medical and mental health providers can be improved that way.

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So we did a randomized trial; they call it PHR versus usual care. The end (ph) was about 170 people, and we looked at patient activities and the quality of medical care that they were getting and health service measures, recovery times, medication adherence, and quality of life indicators.

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First you want to do that. But we started with a program out of Bellingham, Washington called the shared care plan and we collaborated with the developers and mental health consumer leaders to take a look and see what would people need that have mental health, unless there's other people who might not need. We've had (ph) a number of focus groups with consumers, like mental health providers and with medical health providers, and we had some surprises there.

So we went in this thinking, well, you know, consumers, they tend to be poor, unemployed; a lot of them are homeless. They aren't really going to be necessarily interested in it. They're not going to have access to computers. And we were really surprised to learn, actually, that almost everybody has access to computers; that was actually not an issue for us. They know where the libraries are and know what libraries have good privacy screens. They have relatives that have computers. About half of them used the Internet and e-mail on a regular basis, but about 50 percent said that they don't really quite feel comfortable with computers and they could use some training.

Providers; there was a good deal of skepticism in the first place. They wouldn't believe us when we told them that access isn't an issue. They thought that patients would put in medications that - you know, that drug-seeking behavior, so they were pretty suspicious about it. But we found out what - my (inaudible at 0:45:56) they had a really hard time gathering information about the patients, and particularly when it came to the fact you had the diagnoses, because the mental health clinic wasn't sharing any information at the primary health clinic, and they really saw it as an opportunity to get information very quickly.

(Slide)

Okay. But this is kind of what it looks like. Their [actual vid] (ph) looks a lot like the IowaPHR, so we had a family history section, medication section, diagnosis section with educational links, medication section with educational links, a space for them to put in their personal goals. We really found that given an opportunity to tell us what they wanted to be working on was a really good motivator; a list of preventative services overdue for; then also tab these local resources. They could find something if they needed help with housing or any other social services or any other medical services. It was a portal for them to find these things in their community.

We also gave them a chance to track their progress; that allowed them to generate graphs, which they really liked, which we tried this before earlier. It really helped them to visualize the change over time.

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And how did you actually do this? So after we got the focus group and we created the PHR and changed this according to what we heard in the focus groups, we started recruiting patients. And patients that were put in a PHR section met with a nurse case specialist that helped patients for six months with gathering the data that they needed, entering their data. And we're really talking about people really showed up with plastic bags full of paperwork that nobody had put any kind of consolidated organized session before.

And we base a lot of our intervention on the intervention of the nurse on patient activations they measured by the PAM (ph) and to these (ph) people really are. And we still have a good number of people that didn't feel comfortable with computers and the Internet, and so we added a component of computer training classes. So we had people undergo basically a digital literacy screener at the end of the intervention, and then based on that, they met with student nurses that

we hired that they follow up (ph) in a computer assessment tool and computer training tool. And then people had to learn a certain number of things that we felt like were really necessary so they could use the PHR, and then when they graduated from that they got a little reward, and people really liked that component; it was an added benefit to them.

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They explained at great length how the data on the PHR was secure and what they could do to keep it secure. They had a lot of control over what they could show other people, who would it give access to in the PHR and how could they (ph) change this. Especially we also used wallet cards so they could control what showed up on the wallet card and what could not show up on the wallet card.

(Slide)

So, you know, (inaudible at 0:49:34) is that the computer training was really good in keeping consumers engaged on their project. Not only did it give them an added benefit of learning some computer classes and learning, becoming less afraid of the Internet, but it really - we really got to know them. They would see us and say hello. It was easier to follow up with them.

The nursing students that they used were phenomenal. They really worked hard at creating something that the patients could use. And surprisingly, that once the primary care providers actually saw what became of this, they became really excited about it. So as skeptical as they were in the beginning, the more excited they were about it now. They found it enormously helpful, especially the printouts; it gave them a quick snapshot on where the patients were, what was overdue, what the patient wanted to achieve, and I think more importantly it gave the patient a lot of control. If they take it (ph) their provider, the provider could take them more seriously.

One of the issues that our patients face a lot of times is that, you know, they walk in and a provider sees a diagnosis - bipolar, schizophrenia - and they're immediately dismissed, they're not taken seriously, and this gave them a big leg up. It looked professional, it looked organized, you could tell that the information was updated, and so it gave them a lot of control over their conversation with their doctors.

Another thing that we found, and I want to go back to what Dr. Chrischilles said; we had a number of people that we had a hard time engaging in the study, and most of those people tended to be women. And I found it interesting to see that in her data it was the same thing; that men tended to use this more than others.

We ran some focus groups to find out why women are less engaged in this. We thought that it may be they're taking on more family responsibilities and the men tended to, you know - raising grandkids, taking care of the children, and we didn't really get that out of the focus group, so we really don't know at this point why women have lower engagement rate with this.

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So looking ahead, I think the PHR are a really good tool for people to improve their care, and not just because it's more coordinated and it keeps doctors - you know, helps doctors keep a checklist of what needs to get done. But we really think it's an important tool for the consumers to take control of their healthcare. They're keeping everything together. They know what's needed. They can point a doctor in directions that they want to go in as opposed to what a doctor is telling them they need to be doing.

(Slide)

Ideally, of course, it would be that if you could integrate a PHR and electronic system, that was not possible in this setting. You're working and it's still not possible, but you do believe that in a lot of cases it will be possible, and that could take out some of the data entry work that needs to be done.

I also would encourage people, when they're planning an intervention like this, to look at how this works back into the workflow of the clinician. So we talked with the clinicians a long time about at what point it would be good for them to see what they need to see. I mean it was - you know, there is the capability of the patient giving access to the doctor through the (inaudible at 0:53:07) version, but, you know, the doctors just didn't want to open another screen, log into things, and see it. That was not feasible for our clinicians. They really liked the printouts because they could incorporate it into the medical charts and make notes on it and work from there, but that might be a difference in there in a different setting. And that's all, I think. That's it.

(Slide)

ANGELA LAVANDEROS: Great. Thank you, Dr. Von Esenwein. Okay, so at this point we're going to move into the Q&A session. The speakers are on your screen right now. We have received some questions; I'm going to start out with those.

The first one is for Dr. Tang. The question is can you talk about how the PAMF online, or I think we're now calling it My Health Online, interface was developed? For example, did you consult with target patients, conduct usability testings, et cetera? That's the first part of the question.

On a related note, are you assessing barriers to use in adoption, and if so, via what mechanisms?

DR. PAUL C. TANG: Okay, excellent questions. We work with feedback from our patients. We actually had our patients - we have over 160,000 patients online with us now; represents over 60 percent of one of our groups overall. We merged with other groups, so now we're about 55 percent overall.

And some of them, we did annual surveys, satisfaction surveys, and we asked them also if they wanted to volunteer to give us feedback on our interface in particular, so we've had focus groups involving these volunteers to give information.

The other thing we did, as I mentioned, we had alpha and beta tests before going live with our clinical trial, and in each of those, of course, we had people actually using both the web-based tools as well as the home devices and the upload tools, so we did work with patients along the line.

The second question is barrier. One of the barriers we were worried about, well, who's going to use this the most, these tools. Probably the folks who have more chronic diseases to manage. Probably younger folks might have an interest in certain kinds of things they do, like, let's say, Pap smears for younger women, but in general the folks with declining disease are going to be older, and that's borne out in our experience as well. A larger proportion of patients who are on the older side, let's say, over 50 or some over 60, are already online. In fact, we just ran some stats on this, and 45 percent of our patients who are 70 or older are online with us, and 25 percent of folks who are over 80 are online with us.

So clearly sort of this age barrier for digital - for online communication is really crumbling, and that's a good thing. So we think bottom line is that the folks who have the most need for this more continuous access to both their information and to us are more engaged with us.

ANGELA LAVANDEROS: Thanks, Dr. Tang. I actually have another question for you. How do you respond to patients who have unrealistic or unattainable goals; for example, lose 60 pounds in the next three months?

DR. PAUL C. TANG: Well, that's a good question. Well, at the start of the program, this EMPOWER-D, the patient met for an hour-and-a-half. There was a group session sort of orientation in the program, then there's an individual 90-minute session, where the patient and the nurse care manager assigned to that patient discuss shared action plans. And so it's that opportunity where we get to talk about readiness to change and what are realistic goals to help you progress from one station to another. So it's through old-fashioned sort of one-on-one relationship and talking about what's achievable and how do you build on success.

ANGELA LAVANDEROS: Thank you. The next question is for Dr. Chrischilles. What was the control? A different PHR?

DR. ELIZABETH A. CHRISCHILLES: So the control group - thanks for the question - control group in our study is just usual care. So three-fourths of eligibles are invited to use the personal health records; the remainder are just sent a thank you for providing the baseline information, and they'll receive another follow-up questionnaire in six months. So there's no Internet of any kind, so they're just a basic standard care control group.

ANGELA LAVANDEROS: Okay, thank you. The next question is for the speaker panel. Leaving privacy out of the equation for the moment, wouldn't it be easier if service providers data could be consolidated and populate a PHR? There was also a common elephant in the room: Is our privacy actually costing us a lot of tax money to figure out access to data via the patient when the data is already available?

DR. PAUL C. TANG: This is Paul Tang. I will start out and mention what the others - you know, their opinion as well since they use stand-alone PHRs. Our experience is with what I've been calling integrated PHR; that is, it's the patient's view of their EHR, and in addition they have a private area where they can enter information in their PHR that we can't see. But all of the information that we have, essentially all the information we have, is shared with them, and so it's a shared record between their professional healthcare team and they and their caregivers.

So we found that to be very valuable to them and it certainly reduces the data entry, and it just keeps us in sync from an information point of view. But we recognize that we're part of a large system and so most of the folks are getting all of their care and their test results, et cetera, from...

DR. ELIZABETH A. CHRISCHILLES: This is Betsy. I'll just pick up on that, because I think that's a really nice distinction. You know, in the state of Iowa, and actually, in fact, a very large chunk of the country, integrated health systems really are not widely available, and that's where we find ourselves, so it made sense for us to begin with the stand-alone version.

Now, that said, we do have interest in our next - in the next step with linking the personal health record to our epic data warehouse and then using that linkage to populate the PHR with some types of information.

We've been hesitant to do that right away because we really wanted to really focus on this interface component initially from our perspective, getting that right first. So I think there is definitely opportunity to do - especially for a sort of post-discharge follow-up types of disease management programs, and that's kind of where we're positioning ourselves next.

DR. SILKE VON ESENWEIN: This is Silke. I have a couple of thoughts and I don't know if I have the solutions for them. One of the things that we found is that a lot of patients thought that the privacy restrictions about how their medical information gets shared are kind of extreme. And especially when it comes in serious mental illnesses, [as now] (ph) patients have no problem. But then they said, "This is my body, this is my head, this is all part of my healthcare and my doctors need to know what medications I'm on and what's going on with me."

But traditionally, there's quite a while between mental health providers and medical care providers and that's really - a lot of the work that we're doing is integrating the two systems and there's a lot of cultural and traditional barriers between the two and that's really to the detriment of the patient. And people shouldn't assume that patients don't want to share that information, and I think that's something that really needs to be worked on.

You know, that populating (ph) field, I think that sounds really convenient and I like them, but I also know that some people are really disturbed by that. So there was a case, you know, because it's not in our research study, but in some of the insurance-based PHRs, for instance, one of my colleagues, her mother died of breast cancer. And then when she logged into her PHR from her health insurance provider the next month, they already had the populated risk that now she's at risk for breast cancer and that her mother had died from it, and she hadn't entered that

information, and she was very concerned about that; that "Where is my health insurance company getting this information from and why do they feel like they have the right to populate my PHR with all this information? I didn't agree to this." So these are two things that people might want to think about if they're going through this.

DR. PAUL C. TANG: The questioner also asked about privacy, and so I'll build on what someone just said. So in I think all three of ours, we're all care providers; they're covered by HIPAA. Most of the stand-alone providers that were mentioned in the second talk in a slide are third parties that are not covered providers and not covered entities, so they're not providers. So in fact, HIPAA doesn't cover those, and I think that's a real - it's a nuance that patients probably don't appreciate, but it does have real implication in terms of what can happen to their information.

And the other point that was just raised, about both inaccurate claims data and the ability of somebody else entering information in your record, that that won't happen with the provider record either, I think that goes along with the privacy aspect of the question.

DR. ELIZABETH A. CHRISCHILLES: I just wanted to mention, from the standpoint of just medications, we've been very slow to build in a display of a patient's refill history because we've learned from watching older adults with their medication labels in hand, their inability to reconcile what's on that label with sort of a standard comprehensive list of approved medication names. And so we want to look into that a little bit more further, because clearly pharmacies use abbreviations oftentimes, which may make it difficult for them to recognize what they have in their hand and what is on that, My Chart," or what have you, so that's I think an interesting topic to investigate a little bit further.

ANGELA LAVANDEROS: Okay, thank you. And maybe one just (ph) another question. This one is also for Dr. Chrischilles. [Juries held] (ph) the PHRs affecting and/or improving the quality of patient provider interactions and their relationships as well as the clinical outcomes.

DR. ELIZABETH A. CHRISCHILLES: Thanks. You know, I think that's a great question, and I'll be honest and say that when we originally conceived of the project we felt that it would be ideal if we could create, you know, or use a personal health record that had a clinician dashboard and that the providers we're engaged with using. But early on in our physician focus groups, within our practice-based research network, we learned that they weren't ready for that, the providers weren't ready for that, it just didn't fit their workflow and that wasn't going to work, so we don't have that kind of relationship.

However, I think that the communication is supported in a number of ways; one is through the sort of educational messaging about the importance of keeping an active medication list and communicating with your providers, keeping it up to date, taking it with you, and then the report functionality which people seem to be using.

So our feeling is that people who are engaged are using the personal health record, will keep their information more up to date. They'll present to their doctor's office with an already updated

medication list and perhaps a list of conditions that can begin the conversation. And we expect to see what is currently a fairly low rate of comprehensive discussion about medications actually improve in response to questions that we're including in our questionnaire.

So we're really, right now, through the reports function. And I think our older adults told us that they wanted to communicate via paper. They would like to have an ability to update their medication list and just print off a new version.

ANGELA LAVANDEROS: Okay, thanks. Another question actually for you, Dr. Chrischilles. You mentioned I think that you all have not been able to explain why women were less likely to use the PHR, but someone asks if you have any hypothesis.

DR. ELIZABETH A. CHRISCHILLES: Well, yeah, actually I do. And I think we might be able to get at this by bringing people into the laboratory. But in the literature we know that older women tend to lose their fine motor skills more than men. Now, I think men, their fine motor skills, which, by the way, are later to develop in young boys, seem to hold on longer in older men if I'm reading the literature correctly.

So I think it could be partially just their ability to work with, you know, a conventional mouse, for example, and it just may not be a pleasant experience for them, for some of those even (ph), but that's one hypothesis; that it may really be something about their ability to interact with the technology, but I guess that's the extent to which I thought. You think about women being more willing to report about their health and their health concerns, and so it is a bit surprising. I think it merits some investigation.

DR. SILKE VON ESENWEIN: This is Silke. So, you know, our patients are, on the average, in their mid forties, so we don't really see a decline in fine motor skills, but we see the same thing; that women don't engage as much with it as men do, and we try to figure out why, but I mean I don't have any solutions for that at this point.

ANGELA LAVANDEROS: Okay, next question is actually for Dr. Tang. What advice would you have for a small private practice that is trying to find resources for a PHR type approach?

DR. PAUL C. TANG: It's a good question, and as everybody knows, most of carriers (ph) in medical practices are delivered by smaller practices. I think as we - most folks are associated with, let's say, a hospital. And as I'll just rate the program meaningful use incentive program, you know, moves on in the various stages, I think we will have and we've already seen an uptick in - both hospitals, health systems, and physicians practices have EHRs. I think EHRs is an excellent base upon which to build these PHRs. You can certainly start out with these integrated models, and over time there will be another [offer or ability] (ph) to transfer information from one EHR to another and one PHR to another.

But so I think initially it may be piggybacking on the affiliations you have with, let's say, the hospital or health system, because I think you need a certain amount of capital to start these things. But again, I'll refer back to meaningful use; in that program under Medicare an individual

practice, an individual physician, can get up to \$44,000 of funding, and in the Medicaid program it's close to \$64,000. So this money can be used to build out your - implement your electronic health record system, and most of these EHRs also have an attached integrated PHR, so that's a way.

ANGELA LAVANDEROS: Okay, great, thank you. I think it's our final question for the panel, and that is does anyone care to talk about the next steps for their project.

DR. PAUL C. TANG: This is Paul again. I was trying to look up information about the gender differences in our population, and our population, actually females outnumber males in use. And you might guess that - because if you think about the chronic disease model again, we certainly have more females that are living longer and they have more chronic diseases then, and so you would expect hence to have more needs.

So I'm wondering about the demographics; one, we're dealing with more of the older population; two, ours is integrated so that maybe there is a difference in who engages, but it's still an open hypothesis. I found that information interesting about the female.

What's next for us is to move on to monitoring other chronic conditions. In fact, we're going to do one on hypertension, and not just hypertension, but other activities that illustrate your activation in health behaviors, such as using pedometer. We're trying to find ways to engage patients and taking a more active role in their health, not just in an individual disease, so in dealing with cardiovascular disease, whether you're diabetic or not. High blood pressure is still one that this country does not do a good job of controlling; maybe about 40 percent are controlled, and we need to do better to avoid a lot of the downstream complications. So it's more home-based monitoring and online disease management using us as the support team.

DR. ELIZABETH A. CHRISCHILLES: I can take the next - this is Betsy Chrischilles. We have several different directions that we're contemplating going. Our PHR was developed in collaboration with our institute for clinical and translational sciences. And as part of that partnership, we have a commitment to take the next step in linking our personal health record to the research data warehouse that is compiled nightly from the epic clinical information system for University of Iowa hospitals and clinics patients.

And the thought is that we would use this to assist with building patient registries; also, that our personal health record might provide a very nice channel to reach out to our community engagement partners with its federally qualified community health centers of who each have different information systems but who are interested in collaborating with our institute.

And so we thought that the personal health record might be a nice connector to form patient registries and also help store some clinical information in our research data warehouse. So it's a little bit hard to explain it without a picture, so we're, at the short hand, exploring some linkages from other information sources and populations. We also anticipate the disease specific modules and we're looking at the personal health record as also a very efficient way of doing randomized educational intervention trials.

DR. SILKE VON ESENWEIN: This is Silke von Esenwein. We thought about taking this to the next level, having more into our peer network resources we have in Georgia. So instead of having a nurse case manager guide people through the process of getting engaged and taking kind of charge of their healthcare, [a lot] (ph) like tapping into the choice (ph) of peer network is very strong. And to take personal health records to the community centers and [staff the] (ph) centers and day programs around here so more people have access to it and can be guided with peers.

ANGELA LAVANDEROS: Thank you. At this point I do not see any more questions from the audience, so on behalf of AHRQ I want to thank the speakers for presenting today and for their thoughtful responses to our Q&A session. Collin, I'll turn it back over to you.

COLLIN: Okay, thank you very much.

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Please keep an eye out for the next webinar which will be announced, so it will be sent out to you as soon as the materials are ready.

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Again, thank you very much for joining us today. We hope that you have a great afternoon. This does conclude today's session. Take care.